

## EXPERIENCES IN ESTABLISHING A COMMUNITY ARTIFICIAL KIDNEY CENTER

JAMES W. HAVILAND, M.D.

SEATTLE, WASHINGTON

During the past five or more years since we started to consider the establishment of a community center for servicing chronic hemodialysis patients in the Seattle area, we have had a wide variety of experiences. In sharing some of these with you, it is my hope that not only you will learn a little from our tribulations, but also I will carry back from you constructive suggestions for some of our still troublesome dilemmas.

Because he and his associates foresaw how the future trends in dialysis might unveil many problem areas, Scribner approached the Board of Trustees of the King County Medical Society in 1959 or 1960 with the suggestion that the medical society could perform a great public service if it would take the lead in establishing a community artificial kidney center. He told us that at last chronic hemodialysis was practical on a service basis. The mechanical and scientific hurdles had been overcome. The Teflon (and later Silastic-Teflon) cannula had been brought into routine and successful use.<sup>1, 2</sup> It was also brought out that the University was not in a position to continue on a service basis that procedure which it had brought to this point from a purely investigative project. He argued that, in order to prevent another fiasco (such as the one which had occurred several years previously when 10 or 11 hospitals in our area bought heart-lung machines for open heart surgery, yet facilities and personnel existed for proper functioning of but a fraction of these) the medical profession would be living up to its responsibilities if it provided the initiative in planning the development of a community facility for the care of terminal uremics. Naturally there was a good deal of discussion of his proposal for our society had never undertaken a clinical project of this kind or dimension, but in the end we went ahead. A group of civic leaders was chosen to survey available facilities; one hospital (from a list of three candidates) was selected to house the center (Swedish Hospital); an organizational set up was established; an operating grant was obtained thru the generosity of the Hartford Foundation, and we were on our way. It was planned that the Center should become self-sustaining (at some early, but as yet indefinite date). Incorporation

---

From the Seattle Artificial Kidney Center and the Department of Medicine, University of Washington School of Medicine, Seattle, Washington.

TABLE 1  
*Medical Problems*

- 
1. Cannula-related
    - a. Clotting
    - b. Infection
    - c. Septic emboli
  2. Anemia
    - a. Blood requirements
    - b. Iron overload
  3. Peripheral neuropathy
  4. Renal osteodystrophy
  5. Arthropathy
  6. Hepatitis
  7. Gastro-intestinal hemorrhage
- 

TABLE 2  
*Operational Problems*

- 
1. Organization and Administration
  2. Finance
  3. Patient selection (and rejection)
- 

as a nonprofit organization was to be effected as soon as feasible. Now about four years later, we have 21 patients under treatment, representing some 500 treatment-months of care, and it is a real tribute to the dedication of the staff under the direction of our first medical director (John Murray) and his successor (Jerry Pendras) that the Center had been in operation for approximately three years before we suffered our first patient loss. (We have lost three patients up to the present time.)

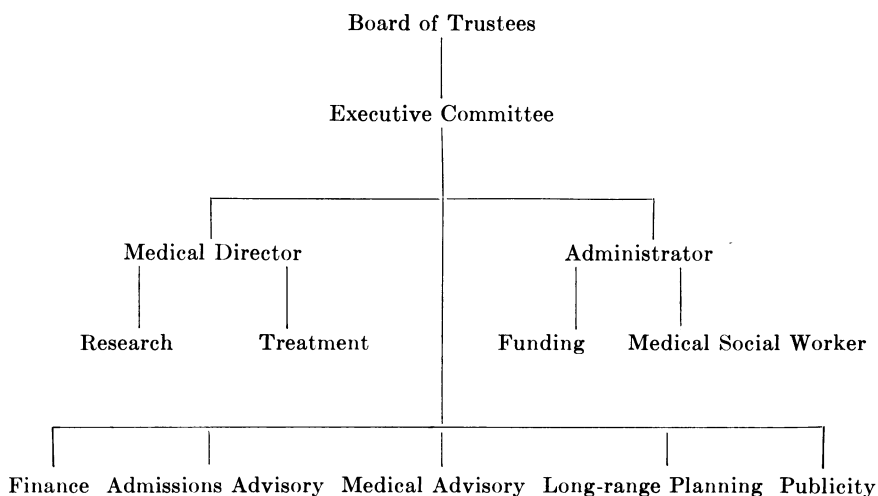
The scientific difficulties encountered in providing this type of treatment are well known from the publications of Scribner et al, Merrill, Schreiner, Kolff and many others.<sup>3-8</sup> I will mention them only in passing (Table 1). Other areas of difficulty which we have met, and which are perhaps a little less well-known, can be divided into (a) organization and administration, (b) finance, and (c) patient selection, and it is to these items (Table 2) that I wish to devote most of my attention. (I might add parenthetically at this point that almost everything we have done in these areas has set some sort of precedent. This has made our life exciting, but all this has been tempered by the realization of the responsibility we had accepted, for the lives of our patients figuratively have hung on the umbilical cord of our decisions, our equipment and our personnel.)

Perhaps the best way to describe our organization is to say that until very recently, it has been a combined bootstrap and shoestring operation. We had nothing to start with and no one to go to. Scribner and his

group felt it likely that a center such as ours could function with a bare minimum of physician coverage, depending instead primarily on trained, competent nurses, attendants and lab personnel. Our original plans called for the Medical Director to act not only as chief physician for the center, but also as director of research, administrator, fund raiser and general public relations expert. In retrospect, it seems as tho we in our ignorance were expecting the emergence of some sort of miracle man. We limped along, but we persevered. We encountered our share of personality problems, but after we became an incorporated body with a Board of Trustees and an Executive Committee, and after we had been given a gentle shove by the United States Public Health Service which reminded us that we had planned to be self-sustaining within three years, we gradually added much-needed staff to help the hard-pressed medical director and his chief nurse. Our Administrator (who functions as Regional Coordinator for the Center as well as fund raiser) was added first, and was followed soon by a part-time medical social worker (who in addition to her more conventional duties performs both as a financial screener, and also as a developer of financial resources for the patients).

Table 3 shows the Center as it is today. Our Board of Trustees is composed of laymen and physicians, and gives representation to business, labor, local government, the clergy, the press, the Seattle Hospital Council, the University of Washington, The Swedish Hospital and the County Medical Society. It has proven most helpful and generous with ideas and

TABLE 3  
*Seattle Artificial Kidney Center—Organization*



counsel. From it is drawn the Executive Committee which meets regularly with the Medical Director and the Administrator to help with the running of the Center by establishing policy, etc. The Finance and Long-Range Planning Committees have self-explanatory functions. The Medical Advisory Committee screens each candidate for the Center and makes recommendations to the Executive Committee and Medical Director based on medical, psychological and psychiatric data. The Admissions Advisory Committee is the well-known "faceless" committee, made famous by *Life Magazine*<sup>9</sup> and is composed of seven laymen and physicians who make recommendations based on other factors and data (moral, ethical, socio-economic, civic, rehabilitation potential and financial). I will go into the actual selection process in more detail later.

An important feature of our organization has been our affiliations. Altho we have been incorporated as an independent organization, we would have been in sore trouble had it not been for the help and support given us by The Swedish Hospital during our first years. Not only were we able to obtain housing for our facility, but also we were able to call upon them for continuity of services such as food, heat and personnel, as well as business administration. When it looked as tho we would run some \$40,000 in the red at one point, the hospital administration expressed willingness to "carry" us until we could work out our financing. When it came time for increasing our bed capacity, they provided more space, undoubtedly at a significant cost to the institution. In other words, without the help and cooperation of The Swedish Hospital, the Center could well have foundered almost before it was successfully launched.

Another affiliation has been the University of Washington School of Medicine. Naturally, with Scribner's unit at the University as the sire of the Center, working relationships have been close. Our physician staff has come from that source. As so often happens, however, the growing child frequently feels his importance and independence. With the exercise of tact and restraint on the part of both parties, nevertheless, and by maintaining good lines of communication at most junctures, it has been possible to maintain the original concept of the Seattle chronic hemodialysis project, i.e., research and development primarily at the University, and patient service primarily at the Center. This affiliation has not been entirely one-sided in its benefits, however. When the University administration feared that it was obligating itself in perpetuity to an increasing number of uremics, it said that Scribner's group could not expand its projects. Research grants could not be sought to study the feasibility of home dialysis and chronic peritoneal dialysis unless provision was guaranteed by some extra-mural group for the continued

care of these subjects on the termination of the grants. After considerable discussion the Board of the Center worked out a formal relationship with Scribner whereby it would "backstop" his research programs. In return for the Center's accepting ultimate responsibility for the patients in the new investigative projects, and in order to maintain a reasonable degree of program continuity for the Center, Scribner agreed to have his patients accepted by the same screening process as for any of the Center's candidates. These negotiations, with the full knowledge of the County Medical Society, have also helped to reduce "town-gown" frictions in our community.

Any discussion of organization and administration would be incomplete if it did not give credit to the people who make up the Center, namely the patients, the staff and the sponsors. The *esprit de corps* among the patients has been remarkable. While selection has been careful, it has not been carried out with an eye to compatibility among the patients. Nevertheless, they have come to be quite a close-knit group, with few exceptions. Their families also have been involved in this grouping. Such camaraderie has been most useful in achieving patient adjustment to the rigors of the treatment routine, but it has also posed severe problems when serious illness or death has threatened any member. Likewise, when incorporation seemed to threaten the imposition of an impersonal Board interested in economic operation rather than patient survival, representatives of the patient group waited on the Executive Committee to assure them, and in turn to be reassured, that the program was to continue with unchanged goals. All in all, however, this *esprit* has been a major plus factor at the Center.

I have mentioned the dedication of the staff. This has involved the giving of care and attention whenever it might be needed, day or night. Even the less skilled members of the team who weigh chemicals, clean and reassemble kidneys, and perform the other routine procedures, seem to sense the importance of their duties and accept their responsibilities with dedication. We have learned the necessity of a well-trained, stable nursing staff. A key item in determining which nurses will join us is their stated intention to work for the Kidney Center for at least a year. Permanence of staff of this order, together with continuity of medical direction not only gives confidence to patients but also permits far greater latitude in discretionary powers to the nurses as the experienced team functions with confidence and spirit. Yet another example of the kind of person attracted to this type of work is our Administrator who, when told that we did not have enough money to cover his salary at first, was willing to work at half salary until he had generated sufficient funds to pay his full salary. Another candidate for this position (a proto-

type of the *Man of Distinction*), a man who gave advance notice of being our best qualified prospect, literally wilted when confronted with this salary proposal. Our "lay sponsors", as we think of our Trustees, have also been most generous with their time and effort. One of them guaranteed the salary of the medical social worker until such time as she could be supported from other sources. We have been most fortunate in our people.

Finances have taken a good deal of our attention, as you may have suspected. We started from scratch, and with the help of the Hartford Foundation we were able to get a good start. Our search for community support was more laggard than we had anticipated, so we were tided over by a decreasing operations grant from the United States Public Health Service. From the very beginning we were told that it would be impossible to get the kind of money we were talking about from our community by means of a fund drive. In fact, we were told very frankly by some of our banker-friends that we should get the necessary funds from the Federal government. This made us just a bit more stubborn than usual about going to the Great White Father, for, if we were to be totally supported in our endeavor, obviously every other community in this country should be able to expect like consideration. Our UGN turned us down, as did several other philanthropic organizations when we talked in terms of a minimum of \$10,000 a year for each patient for the indefinite future. At time went by, we also realized that we were facing another unexpected problem. Not only was successful organ transplantation becoming a more elusive *Will O' The Wisp*, but also our own patients were being treated far more successfully than anyone had ever dreamed would be the case. We had expected initially that perhaps two or three years would be the life expectancy at the very most. Now we were approaching and passing the four year mark, with no end in sight. Our financial projections were just about wrecked by our good results, and all this made it just that much harder to get any community group to assume continuing financial responsibility for our growing brood. In considering all the factors and advice given us by our friends, it became increasingly evident that the number of patients to be served would be too small to generate mass community support of the order necessary for hemodialysis. Consequently, we hit on the plan to make our chief support patient-centered. By this I mean we now start with the concept of making the care of each patient a financially self-sustaining unit as nearly as possible. Our medical social worker works with the family to determine what resources they may have. Then she helps them put together a financial package for at least the first three years of care. This may involve relatives, employer, insurance carrier, church or

other community group, governmental agency with some responsibility for medical care of the patient, and the like. To date we have been reasonably successful. However, there has been the other group of potential candidates for whom reasonably adequate financing could not be arranged. For these, and for the total operation of the Center we have been able to get some financial help by way of legislative appropriation, and at present we are engaged in a general fund drive in the state, particularly in the communities from which we have derived our patients, in order to adequately supplement our other funds.

Our experience to date leads us to believe that patients selected for care without regard to financial restrictions (as was true of our first 12 patients who were completely supported by grants at the outset) can be expected to generate approximately 30% of current costs. Whether finesse at ferreting out additional sources of funding, aided and abetted by decreasing costs of operation will substantially increase this percentage remains to be seen. Certainly insurance (particularly "major medical and catastrophic coverage") has proved an unexpected boon. We have been fortunate in having an insurance broker on our Board who has been invaluable to us in our negotiations with various carriers.

I would be remiss if I did not admit that at one stage of our financial crises we were hard-nosed enough to refuse admission to any candidate who was not fully supported for three years. Our reasoning was that we had accepted full responsibility for the lives of 12 patients, and we did not feel that we should jeopardize these lives by accepting others before we were on a firmer financial footing. Thanks to the untiring efforts of our Administrator to make our operation more efficient and more nearly self-sustaining, our annual deficit has been reduced from \$40,000 to \$30,000 and now to less than \$3,000, at the end of our most recent fiscal year. This also had been made possible by the fact that our annual per patient cost recently has fallen below the previously mentioned \$10,000 per patient per year figure. Such improvement in our financial outlook has permitted us to ease the fiscal strictures on entering patients just a bit when necessary. Naturally, since patients are billed for actual costs, these savings have been passed on to them. Finances, while not entirely solved, seem to be more nearly under control at the moment than at any time since inauguration of the program.

Finally, I would like to spend a few minutes discussing the subject which led me to submit this paper for presentation, namely, patient selection (and rejection). I suppose that this general problem has generated most of the philosophical controversy that has revolved around chronic hemodialysis. For what I believe are fairly obvious reasons, we have established rather rigid criteria for admission to the Center, and

TABLE 4  
*Admissions Criteria*

- 
1. Stable, emotionally mature, responsible citizen.
  2. Absence of long-standing hypertension and permanent complications.
  3. Demonstrated willingness to cooperate.
  4. Age (17-50 years "physiologically").
  5. Slow deterioration of renal function (creatinine 8-12 mg. %).
  6. Six months' residence in area.
  7. Financial support.
  8. Value to community.
  9. Potential for rehabilitation.
  10. Psychological and psychiatric compatibility.
- 

we have stuck by them. Table 4 shows these criteria. Originally the age limits were set at 25-45 years of age in order to give us those "most likely to succeed", but with experience these limits have been expanded gradually. To date it has not seemed feasible to go below late adolescence (17-18 years of age) because of doubtful patient cooperation, and our fear of being unable to support normal growth and development in children, and as yet we have accepted no one over 60. We arbitrarily established the requirement of six months' residence in our five state area (Washington, Alaska, Idaho, Montana and Oregon) before application for treatment could be made. Experience showed that it was difficult to justify use of local funds for people beyond this area. Also it proved difficult to ensure job stability and exploitation of rehabilitation potential even within this large geographical limit if the patient resided a considerable distance from Seattle. Personal responsibility and value to the community are rather ill-defined, evanescent characteristics, to be sure, but in a sense they interdigitate well with potential for rehabilitation, on which we have laid great stress.

Through bitter experience we and others have learned that chronic dialysis (especially home dialysis) imposes an important additional psychological burden on the patient. To some patients it can become a fate worse than death. Furthermore, it is important to realize that nothing is harder on the staff and the other patients than coping with a chronically unhappy, mal-adjusted patient. Hence in our view, rather vigorous psychiatric screening will have to continue to be a necessary, though unpleasant part, of the operation of a successful chronic dialysis program until such time as technical advances make the treatment easier to handle for staff and patients. With regard to psychological and psychiatric compatibility, we have paid particular attention to the evaluations by our consultants in these fields. Perhaps this is one more reason why we have had unusual success in gaining patient cooperation.



Earlier in discussing the organization of our Center, I touched on a portion of the selection process. When a candidate for treatment is proposed by a physician or other source, he is considered by the Medical Advisory Committee which considers not only medical indications, but also psychological and psychiatric factors. A financial evaluation is begun immediately and data on the other factors to be considered are collected by the medical social worker. All this information is available to the Admissions Advisory Committee for its deliberations, and the final approval is given by the Medical Director with the backing of the Executive Committee. This may seem like a rather cumbersome procedure, but since we have elected to make this a selective process, and since some of the decisions are fraught with much emotion (as when a patient is rejected), a measure of protection is afforded to the various selecting bodies and no one factor is permitted to bear the brunt of responsibility for rejection. At any point during the selection process, candidates may withdraw for personal reasons. In fact, I am sure that we would never insist that a patient continue with dialysis, if at any time he should no longer wish therapy, and so far no one has withdrawn after starting treatment.

It might be interesting to spend a few minutes in considering some of the patients who have been rejected by this selection process. There was the beatnik—in his mid-twenties, doing poorly in college (in spite of considerable effort on the part of his faculty sponsor), poor job record, and apparently without funds or plans for the future. He just did not seem to fulfill the criteria of value to the community and rehabilitation potential. There was the lady of ill repute (a veritable Camille)—and altho she had plenty of financial support, it was not felt that she could be considered a responsible citizen and her potential (interest) for rehabilitation seemed limited. A final example is the logger who seemed to qualify in every way, except that our staff and his employer simply were unable to put together any semblance of a financial package for his continued care. He expired the same day a letter of rejection and explanation went to his wife. Altho in retrospect they seem fairly straightforward, these decisions have not been easy. Rejection invariably has called forth lengthy soul-searching by the various deliberative bodies. In a sense rejection has made some of the staff feel they have failed the candidate. We have been accused of “playing God” by this process of selection, but with limited facilities and limited financial backing and nowhere else to turn for help, we experienced (many of us for the first time) the choice of taking patients on a first come, first served basis or by means of a super-triage system. We elected the latter course. Altho it may smack of smugness, we have been fairly well satisfied with our

TABLE 5  
*Patient Rehabilitation*

	Former Occupation	Present Occupation	Hours Worked Weekly
J.A. ....	Graduate student	Assistant professor	45
S.A. ....	Registered nurse	Registered nurse	24
D.B. ....	Homemaker	Homemaker	24
D.D. ....	Business executive	Business executive	40
P.F. ....	Electrician	Office worker	40
K.H. ....	Construction	Homemaker	24
C.L. ....	Ophthalmologist	Ophthalmologist	40
M.L. ....	Homemaker	Homemaker	36
J.M. ....	Manager, Lumber Co.	Manager, Lumber Co.	16
M.M. ....	Student	High School teacher	50
M.M. ....	Homemaker	Homemaker	24
J.M. ....	Manager, Oil Co.	Manager, Oil Co.	40
L.O. ....	Homemaker	Hospitalized	0
S.S. ....	Bookkeeper	Bookkeeper	40
F.S. ....	Mechanical engineer	Mechanical engineer	50
F.W. ....	Homemaker	Homemaker	36
C.Y. ....	Photographer	Photographer	54
B.F. ....	Milkman	Unemployed	0
E.S. ....	Construction executive	Construction executive	40
F.T. ....	Orchardist	Orchardist	?
M.L. ....	Housewife	Housewife	24
F.W. ....	Housewife	Housewife	24

procedure, especially when bed space has been in short supply or not available for a desirable candidate.

It may be of interest to look at just what our patients are doing with their time, just what does "rehabilitation" mean, just how effective have our efforts been. Table 5 shows this in summary form.

Finally, there is still another troublesome facet to this general problem. Patient selection or rejection requires the use of judgement which emphasizes new ethical parameters. How far can we go with such a selection process as I have outlined? Natural selection up to the present has depended largely on availability of treatment and ability to finance it. The highest quality care is now a "right" of all in "The Great Society". Does failure to live up to these new standards make us unethical? Of more practical importance is the ethical question raised when we are asked to save the life of a terminal uremic "for a little while so that a 'critical' experiment can be performed". If such a patient is accepted for such a project, it poses a problem for us eventually. Who has the right, the duty or the privilege to make the decision to "turn off the machine"

when the experiment is over? There is also the problem of the proper training of house officers in ethical behavior. Is such a request ethically acceptable? A somewhat different situation has arisen when patients suffering from otherwise fatal conditions are proposed for rather short term dialysis simply in the course of their necessary medical care. These patients may be rejected for care "because the patient is going to die anyway", or "because it's an awful lot of work to put in on someone who is dying!" To one looking on from the outside, it seems as though some of the younger staff men and trainees are learning to make life and death decisions rather quickly and easily. Is it ethical for us to treat these momentous decisions thus lightly? Lastly, in a field of human experimentation such as chronic hemodialysis, when we really don't know precisely what the patient has to look forward to, how far are we justified in encouraging patients and their families to sacrifice for the benefits of this therapy? The Helsinki Declaration<sup>10</sup> and its expansion by the British Medical Research Council<sup>11</sup> place benefit to the patient as the paramount consideration, and emphasize full explanation to the patient as essential. I wonder if we always do this, in the flush of favorable experience?

### CONCLUSIONS

1. Experiences in the formative years of the Seattle Artificial Kidney Center have been set forth.
2. Particular emphasis has been placed on the organizational, administrative, financial and patient selection (or rejection) features of the Center's operations.
3. Some new ethical implications raised by chronic hemodialysis are discussed.

### REFERENCES

1. QUINTON, W. E., ET AL.: Cannulation of Blood Vessels for Prolonged Hemodialysis. *Trans. Am. Soc. Artif. Int. Org.* **6**: 104 (1960).
2. QUINTON, W. E., ET AL.: 8 Months' Experience with Silastic-Teflon By-Pass Cannulas. *Trans. Am. Soc. Artif. Int. Org.* **8**: 236 (1962).
3. SCRIBNER, B. H., ET AL.: The Treatment of Chronic Uremia by Means of Intermittent Hemodialysis: A Preliminary Report. *Trans. Am. Soc. Artif. Int. Org.* **6**: 14 (1960).
4. PENDRAS, J. P. AND ERICKSON, R. V.: Clinical Experience with 16 Patients on Chronic Hemodialysis. *Trans. Am. Soc. Artif. Int. Org.* **11**: 238 (1965).
5. SCHUPAKE, E., AND MERRILL, J. P.: Experience with Long-Term Intermittent Hemodialysis. *Ann. Int. Med.* **62**: 509 (1965).
6. SCHREINER, G. E., ET AL.: Hemodialysis for Chronic Renal Failure. *Ann. Int. Med.* **62**: 519 (1965).
7. KOLFF, W. J., ET AL.: Pathological Anatomy of 13 Patients after Prolonged Periodic Hemodialysis. *Trans. Am. Soc. Artif. Int. Org.* **9**: 21 (1963).

8. BRANDON, J. M., ET AL.: Prolongation of Survival by Periodic Prolonged Hemodialysis in Patients with Chronic Renal Failure. *Am. J. Med.* **33**: 538 (1962).
9. *Life Magazine*, p. 102. 9 Nov. 1962.
10. The Declaration of Helsinki—Human Experimentation (Code of Ethics of the World Medical Association) *Brit. Med. J.* **2**: 177 (1964).
11. Responsibility in Investigations on Human Subjects (Statement by Medical Research Council of Great Britain). *Brit. Med. J.* **2**: 178 (1964).

#### DISCUSSION

DR. FRANCIS C. WOOD (Philadelphia): Would you give us some idea of the total number of patients in the Seattle area that have applied as compared to the number that you have been able to accept?

DR. HAVILAND: Of course this is a skewed distribution, Dr. Wood, because for a while we did not accept anybody who was unable to pay. However, our experience has been pretty well in line with the prediction we originally had that, disregarding finances, we can expect about 25 suitable patients per year per million population. This is the basis on which we have gone, and on which we have talked with people in other areas.

DR. WALTER L. PALMER (Chicago): I think this is a fascinating report and Dr. Haviland and his group certainly are to be congratulated on a wonderful cooperative effort. I sympathize personally, too, with the attitude you have with respect to not approaching the Federal Government, but I would like to raise the question whether or not with this new great society concept we now have, are you any longer justified in refraining from approaching the Federal Government? It seems to me that if they are going to support everything else, this certainly should receive federal support.

DR. HAVILAND: I might say that we have not turned down federal money that was given to us. We did have a Public Health Service grant and we certainly have been most grateful for it. Also, there is legislation now under consideration at the present time with regard to this same problem, and I am sure we will have our hand out with the others. However, it did seem to us that as a starting gesture, rather than to stop all efforts of community self-support, it was important to not look to the Federal Government first off, which was the first line of resistance on the part of some people.